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ABSTRACT

This paper describes the second year of a 5-year study of the needs of individuals with disabilities as they relate to consumer products. The study employed focus group research techniques in which group members responded to issues and raised their own concerns regarding general products and equipment specially designed for persons with disabilities. The study involved three groups; each group consisted of persons with the following disabilities: cerebral palsy, multiple sclerosis, stroke, and traumatic brain injury. Focus group discussions often included areas beyond the realm of technology, such as the need for more and affordable services to assist persons with disabilities, the need to combat ignorance and stereotypes, the need for companionship and socialization, and others. Product features cited by focus groups included cost, durability, maneuverability, ease of assembly and disassembly, reliability, controls, safety features, simple instructions, aesthetics, and ability to keep devices in place during use. Other issues discussed included information sources about products, difficulties in choosing devices, trade-offs in using devices, and consumer interest in testing devices. Specific types of products are examined, including controls, computers, mobility devices, kitchen appliances, grooming and dressing devices, and communication tools. The report presents "wish list" items compiled by each disability group, and concludes with creative solutions used by focus group members to cope with their needs. A moderator's guide for focus group discussion is attached. (JDD)

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DESIGN FOR ALL

CONSUMER NEEDS ASSESSMENT PROJECT YEAR 2

RESULTS OF THE SECOND YEAR OF A FIVE YEAR STUDY

Carolyn Ward

July, 1990

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Rehabilitation Engineering Center
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INTRODUCTION

> ...when they design something, a food processor or anything like that, they should design them for all people in mind,...nobody's perfect...there's always going to be somebody that's different. But, if you could design it with more of a general idea of who's out here...that would be a lot better than some of the stuff made today.
>
> -- a Focus Group Member.

The concept of designing products for all people was proposed repeatedly by persons with disabilities who participated in the first two years of a five year Electronic Industries Foundation Rehabilitation Engineering Center (EIF/REC) research project. Yet this suggestion, simple as it sounds, is fraught with many difficulties. How can the needs of persons with disabilities, a most diverse population, be identified? Who can explain what these consumers require? By what means can those needs be translated into the creation of appropriate and available consumer products?

In 1988, with funds from the National Institute on Disability and Rehabilitation Research, the EIF/REC began soliciting the ideas and opinions of persons with disabilities about their technology needs. The Consumer Needs Assessment Project employs focus group research techniques, time-limited meetings where a trained moderator poses a broad range of questions to small groups of participants (usually between eight and twelve persons). Focus group members are asked to respond to those issues and to each other, and to raise their own concerns. Through this process, the EIF/REC is collecting data on both general consumer products, such as computers, telephones, televisions, and ovens, as well as on equipment specially designed for persons with disabilities, such as canes, or augmentative communication devices.

The aim is to learn directly from users about their experiences with products, what design features make a product work for them, and what features make a product inaccessible. Since a demand for products does not exist in a vacuum, participants in this study are given an opportunity to comment on needs beyond technology that influence their ability to function in daily life.

Each year, project research findings are analyzed and published. (1) These monographs supply information about the needs of consumers with disabilities to those capable of translating the results into actual devices and services. The reports are distributed to device manufacturers, rehabilitation professionals, policy makers, and members of the general public. Analyses are also presented at professional conferences to broaden the dissemination of information. This document covers the findings of the second year of the project.

GROUP DEMOGRAPHICS

In year two of the Consumer Needs Assessment Project, the EIF/REC convened three groups each of persons with the following disabilities: cerebral palsy (CP), multiple sclerosis (MS), stroke, and traumatic brain injury (TBI). The focus group sessions were held in the Northeast, Midwest, and Southwest.(2) As in the first year of the project, the participants were not randomly selected. Local organizers were instrumental in recruiting participants through programs in an independent living center, a rehabilitation engineering center, a school, rehabilitation and hospital facilities, volunteer organizations that sponsor support groups, and adult day health services. Therefore, all those who participated in the sessions were affiliated with the social services network on some level.

A broad range of individuals was involved, from teenaged students to older retired persons. Group members represented both sexes and different races. Their socioeconomic, educational, marital, and employment status varied. One of the stroke group sessions, held in the Southwest, consisted of newly disabled persons. For the most part, however, the participants had experienced living with a disability for several years at least or for much of their lifetimes.

Several departures were made from the original structure of the first year of the project.(3) Group discussion was lengthened from ninety minutes to between two and three hours to allow for increased discussion of product issues. Instead of examining one's routine in a typical day, the discussion centered more directly on appliances used both within the home and when one entered the outside world. The emphasis was on features that participants liked or disliked about devices and their ideas for product improvement. In several groups, due to communication problems, personal care attendants or family members acted as interpreters for nonverbal participants. In accordance with year one of the project, questions regarding wish lists for specific devices and creative solutions to technological problems were posed. Time was provided during the sessions so that participants could discuss needs that were unrelated to product issues (see Attachment 1, the Moderator's Guide).

Although each group consisted of individuals whose disability was identified within a specific diagnostic category, in some sense those groupings proved to be artificial boundaries. While there seemed to be a strong spirit of camaraderie within the focus groups themselves, great diversity existed as to how participants identified their limitations, their needs, and their concerns. A recurrent theme was that as no two people are alike, needs differ. One size does not fit all. Transcending diagnostic groupings, however, common trends did emerge and were identified within the different focus groups.

WHY USE FOCUS GROUP RESEARCH TECHNIQUES?

In the EIF/REC study, focus group techniques provide information to researchers that is not otherwise available. Traditionally, consumers with disabilities have not been the subjects of market research. Few studies exist describing their attitudes towards the products they use.(4)

Such research is beneficial in other ways. Focus group methodology allows participants to share information and learn from the experiences of fellow members. They express their opinions and feed off of each other's ideas. Participating in a non-judgmental, non-threatening forum where their unfiltered viewpoints are aired and heard, group members often recognize their ability to be resources to one another. For instance, during the course of a focus group session held in the Southwest of persons who had sustained traumatic brain injuries, a participant recommended that consumers in the group start a column in their local Head Injury Association newsletter to exchange product information among themselves on a regular basis. In the Northeast, during a focus group meeting of persons with multiple sclerosis, a participant expressed the need for a vegetable slicer, something she had never come across. Fellow group members informed her that such a device already exists, and where to obtain it. These scenarios occurred throughout the focus group sessions held in the second year of the project.

BEYOND TECHNOLOGY: OTHER NEEDS IDENTIFIED WITHIN FOCUS GROUPS

Although the goal of the EIF/REC research effort is to learn about the product needs of persons with disabilities, focus group discussions often turned to areas beyond the realm of technology. Generally, focus group members eloquently identified problems that affected both the quality of their lives and their ability to handle daily tasks. Several of these issues were raised in the first year of the research project; others cover new ground. A sampling of the needs identified includes:

- The need for more and affordable services to assist persons with disabilities, including medical rehabilitation programs, quality job training programs, medical research geared to improving physical and/or cognitive functioning, information and referral assistance, advocacy, and education for persons with disabilities and their families and friends on coping with functional limitations.

- The need to combat ignorance and stereotypes about persons with disabilities that result in discrimination by society at large. When asked about "wish list" items, one member of the Northeast MS focus group simply said, "More understanding." Focus groups often disagreed as to how that goal could be accomplished. Some people cited passage of the Americans with Disabilities Act (ADA) as a way of changing

attitudes. Others suggested mass media campaigns and enforcement of current laws on the books. There were still others who felt the only way attitudes would change would be if people were personally affected by a functional limitation (either having a disability themselves or coping with one within the family or among their friends).

- The need for companionship and socialization. While technology and its potential were recognized by the majority of focus group members, several participants did not view technology as a primary personal need. They felt isolated and sought human contact, at home or through social service settings (such as adult day health programs for persons who have experienced strokes or in the case of some persons with traumatic brain injuries seeking group housing situations). Another part of that equation includes an upgrade in status and pay for personal care attendants, which was discussed by the Southwest multiple sclerosis focus group. Summing up the need, a participant in the Southwest stroke focus group explained, "...it's not so much something that you would put on my trailer that would make my life more comfortable. It's the attention and sociability and the communication with somebody...."

- The need for affordable, compassionate medical care. Several focus group members supported the idea of socialized medicine. Attitudes towards the quality of care and communications varied, but many felt strongly that reforms were needed in the system. Suggestions for improving medical care also included a recommendation by the Northeast traumatic brain injury focus group that involved having trained peer counselors with disabilities in hospitals and rehabilitation programs to provide emotional support to newly injured persons.

- The need to untangle the maze of benefits available to persons with disabilities. Many people raised concerns about Social Security Disability Insurance (SSDI), tax deductions, private insurance coverage, and other benefits that might be available to them, but about which they lacked knowledge. The importance of information dissemination on these funding issues is perceived as crucial.

- The need for user friendly, reliable, low cost public transportation and increased accessibility to the outside world through, among other things, gently sloping curb cuts, spacious handicapped parking areas, ramps, railings on both sides of stairways, and tread-operated doors. As one focus group member commented:

> The biggest problem is the definition of the word accessibility. Accessibility to one person does not mean accessibility to another person. You can call a restaurant or wherever you go, and you find...either the doors are really not wide enough or the aisles or something doesn't fit....

(The issue of access to the world outside of one's home will be handled in more detail in a separate section of this monograph, since it was identified as a need both in the first year of the study and in all twelve focus groups convened in the second year.)

Recognizing and responding to these perceived needs is a complex process. These issues, however, affect the ability of persons with a wide range of disabilities to actively participate in the life of society at large. Participants pointedly asserted that these concerns must be addressed in a timely manner. How these goals are to be accomplished is truly a matter of public debate and policy.

PRODUCT FEATURES CITED BY FOCUS GROUPS

Although the people interviewed within specific focus groups and across diagnostic categories defined their technology needs broadly, certain product features were repeatedly mentioned as important to consumers with disabilities. In the first year of the study, needs were defined within the following categories: safety/health, privacy, independence, convenience, and employability.(5) All of these issues resurfaced in the current year of the project. This time, however, the product needs were more specifically identified. The characteristics cited were:

- cost;
- durability/strength;
- maneuverability/portable nature of devices;
- ease of assembly/disassembly;
- repair concerns/reliability;
- the height, location, size, texture, color, and brightness of switches, knobs, dials, and buttons;
- safety features;
- simple, easy-to-understand/follow instructions;
- aesthetics; and
- ability to keep devices in-place during use.

Each of these features will be considered in turn.

COST

Whether the device is a piece of adaptive equipment or a general consumer product, those who participated in the Year 2 focus groups made clear that cost is a major obstacle to obtaining technologies. This finding is consistent with results from the first year of the project.(6) A Southwestern stroke focus group member explained his situation this way, "...everything costs money, everything costs money. My bills, you can just imagine, I've got a stack of bills that high." As a participant in the Northeast MS focus group said, "...an innumerable number of things...make a house more liveable. The question is funding...as everyone here, you're faced with a budget." In the words of an attendee of the Southwest multiple sclerosis focus group, "...a lot of things that would help us are so expensive that we don't have access money to them."

Although many focus group members wanted all kinds of devices, from computers and kitchen appliances to adaptive equipment, the costs of these products were cited as being beyond their financial reach. However, participants gave few specific examples of what price tag would make a specific technology affordable to them. One member of the Midwest cerebral palsy focus group discussed the need for an electronic mixer with a bowl, since his spouse, who cooks for the family, has the use of only one hand. In pricing such appliances, he found the average cost was about $140. That figure was beyond his means. He felt he could afford something in the $25 to $50 range. Another group member considered the issue of medical supplies, saying:

> People have got to have them, and they [manufacturers] know it and that's why they cost so much money to get them. Like crutches, okay,...these, they're not so bad, they're $20 or $30, but the metal ones with cuts, they range anywhere from $80 to $160. That's ridiculous. They're just a piece of aluminum and that kind of thing. Batteries for chairs or other things, they're $50 or a $100 a set and that's too much, that's terrible.

Comments such as these were the exception to the rule, however. For many focus group members, it is difficult to go out and attempt to do any form of comparative price shopping. So, although the cost of equipment is a definite barrier for persons with disabilities, not enough information is currently available to ascertain what charges would cause these consumers to purchase items they want but cannot finance.

DURABILITY/STRENGTH

Another recurrent theme among focus groups is the need for sturdy equipment that is able to withstand lots of use and unintentional abuse. Several people asked that devices be created so that they are difficult to break when dropped repeatedly. Examples given

included laptop computers and telephones. Since many participants use wheelchairs daily, they sought models that could absorb the impact of functioning on a variety of terrains and being constantly hoisted into and out of the back seat or trunk of a vehicle. As one of the members of the Southwestern cerebral palsy group remarked about wheelchairs, "There are these vans, and they [the wheelchairs] have to be tied down and all this, and these bumps they have to take, it's a lot of wear and tear on the chairs." Consumers want durable equipment that they can rely on with assurance.

MANEUVERABILITY/PORTABLE NATURE OF DEVICES

In addition to sturdiness, consumers seemed to favor products made of lightweight materials. Focus group members explained that this quality is attractive because it allows them to lift and easily move the equipment either independently by themselves, or to make it less burdensome for persons assisting them with a device. No matter if the device is a vacuum cleaner, a kitchen utensil, a brace, or a cane, light weight, space age materials are perceived generally as an improvement in fashioning technologies. As a member of the Northeastern CP group stated, "My motorized wheelchair, I have one, it's pretty big. Could they make it smaller and lighter? That thing is heavy and I'll have trouble maintaining it myself when it breaks down...." Two cautionary notes about lightweight materials came from the Northeast MS focus group and the Southwest cerebral palsy group. The first concern identified was whether their cost would be so prohibitive that individuals would not have access to these products. The second issue was whether such substances were sturdy enough to withstand stress. For the most part, however, focus group participants praised and wanted materials that make a device easier to manage or maneuver.

EASE OF ASSEMBLY/DISASSEMBLY

Many devices require multiple steps to assemble and dismantle. Locking and unlocking a rollator (a type of walker), or placing a cane in a holder that allows it to sit on a table, for example, requires a level of strength and dexterity that many focus group members cannot muster. The same goes for using a food processor. Its multiple components and tight lid make it hard for many consumers with disabilities to operate. Other devices mentioned included plugs and electrical outlets, and electric can openers.

This problem does not only exist for products with many parts or steps to accomplish their function. Medicine bottles (particularly those with "child proof" safety caps), toothpaste tubes with separate screw tops (as opposed to the relatively new flip top caps and toothpaste pumps), or twist ties on food packaging are bothersome obstacles to many who participated in the focus groups. Manufacturers taking this need into account can

broaden the audience for their devices by making them easier to utilize for the public at large.

REPAIR CONCERNS/RELIABILITY

Several groups shared horror stories regarding devices that broke down and took a long time to repair or replace. In fact, in the cerebral palsy focus group in the Southwest, one nonverbal participant was limited in her ability to let her ideas be known because her electronic augmentative communication device needed a $500 power supply. Since there were plans to replace the board with a new model, she was left on hold, requiring a personal care attendant to act as her interpreter.

Consumers spoke of acquaintances who had planned to attend the focus group meetings, but were unable to do so because equipment they depended upon (e.g., an electronic wheelchair), was in the shop. In the Southwest TBI focus group, a member suggested lengthening the warranties on products so that repairs are covered and equipment is kept operational and in the Northeast traumatic brain injury group a participant felt that device repairs should be financed through some kind of general fund. While some focus groups found this to be more of a problem than others, depending on the type of products they used, it is an issue that was repeatedly identified.

THE HEIGHT, LOCATION, SIZE, TEXTURE, COLOR, AND BRIGHTNESS OF SWITCHES, KNOBS, DIALS, AND BUTTONS

Controls that activate a device can be constructed so that consumers with different types of disabilities can independently use the product. Those unable to stand or bend may require switches, knobs, dials, or buttons located at both wheelchair height and in the front of a piece of equipment. For instance, a stove with dials at the back of the appliance can be both difficult to reach and a safety hazard to someone who cooks from a seated position, or who has problems with balance, sight, or seizures, as did many of the focus group members.

Those with hand-eye coordination problems, tremors, or visual limitations can benefit from big controls or more room between the controls. "The bigger the better" was the consensus among focus groups as a way to improve controls. Large controls are easy for many persons with diverse disabilities to manipulate.

The texture of controls can affect how easily consumers with disabilities can operate them. A smooth push button, for instance, is problematic for the person with limited tactile sensation or visual impairments. A member of the Northeast MS focus group suggested

that an extended or indented push button can help guide a consumer to use such a control effectively.

Other changes can make products simpler to employ for persons with disabilities. Some people cited color coded or contrasting switches that can show a person with memory or visual problems how to adjust a control. While there was diversity in the type of controls individuals identified as easiest for them to use, control height, location, size, texture, color, and brightness consistently influenced focus group members' ability to utilize devices.

SAFETY FEATURES

Group members recognize the dangers inherent in improperly using appliances in the home. They seek additional cues and prompters, like a voice or a flashing light, to either remind them to turn off an appliance when it is no longer in use (like an iron or an electric heater), to inform them that the device is switched off automatically after a period of time, or to instruct them in an action (e.g., to take medications in a timely manner). Some also want safety guards on appliances like electric carving knives, to protect against injury. As a member of the Northeast MS focus group observed, "Well, my hand trembles. So, straight edged razors are out the window and rotary razors, they threaten my lip. An arm stabilizer would make it a heck of a lot easier."

Devices that are sharp or hot are considered hazardous. Many people discussed the advantages of using microwave ovens as opposed to the stove, since the likelihood of burning themselves is diminished.

Safety features also came under review when focus group members spoke about the ways they summoned help. Several group members depend on emergency alert systems. One woman in the Midwest TBI focus group identified her emergency alert system as her "parole," allowing her to live alone. Other focus group members said they carry cordless phones with them to make contacts in the event of an accident. For a nonverbal participant in the Southwest CP group, the telephone company placed a special tone in the telephone that she can push which can send out a signal to alert the police and the fire departments, if necessary. Clearly, safety features provide group members peace of mind when using products. Many have put a lot of thought into how to respond to emergency situations when help is not immediately at hand.

SIMPLE, EASY-TO-UNDERSTAND/FOLLOW INSTRUCTIONS

For many people who have memory limitations, directions for using devices are a problem. According to a Midwest participant in the traumatic brain injury focus group,

"Mostly, I didn't understand things real well. My mind made things out to be harder than they were. Like if there were several steps to things, it was hard to follow things in order." Microwaves and videocassette recorders (VCRs) were often cited as having too many programmable functions, making them difficult to figure out and use. Sometimes family members in attendance to assist their relatives at the meetings chimed in and remarked that although they did not have a disability, they found the same difficulty with such products.

Consumers with disabilities were very eager to recommend how this situation could be alleviated. One participant observed, "...keep it very simple -- yes, no, on, off...." Besides limiting the number of functions within a specific device, suggestions included putting product instructions into plain English. Computer manuals were specifically identified as culprits. Consumers do not want to be overwhelmed by the multiple capabilities of products or confusing instructions.

AESTHETICS

Although there was some diversity of opinion over the importance of aesthetics, many consumers felt that adaptive equipment, in particular, ought to be designed to look less medical in appearance. This idea was forwarded by a participant in the Southwest MS focus group, who said, "...when you're dealing with people with handicaps, I think more than even the average person, you need to try to make an item, whatever it is, pretty, fun in some way, something to brighten their life." This group discussed in detail the importance of keeping one's house looking like a home rather than a hospital. There was even some discussion as to whether people would use certain devices more often if they perceived them to be attractive.

In the Northeast CP focus group, there was a divergence in outlook. One person remarked, "Hey, as long as I can get around, I don't care if it [a product] looks like a monkey." However, another attendee responded, "Sometimes, I do care when people do stare at me...." Aesthetics were certainly not a regional issue. People in the Midwest traumatic brain injury group wondered, "Is there any way you could glamorize a cane?" One member of that group talked about how the first thing people notice about her is the walker she utilizes. She felt there was a stigma attached to the device.

So making equipment stylish and appealing are product features mentioned by many consumers with disabilities. One participant stated, "...I don't want to draw extra attention to myself, thanks. She's got a problem, look, she needs that...you don't need a neon sign...." Attractive products can help to make a difference in the attitudes of those employing them.

ABILITY TO KEEP DEVICES IN-PLACE DURING USE

In all diagnostic groupings of consumers the EIF/REC convened in the second year of the project, participants discussed the problems of operating devices that are created for people who have the use of their two hands. Activities such as buttering bread, setting digital alarm clocks, utilizing a computer, tying shoes, or trying to take notes when speaking into a traditional telephone are only a sampling of the types of tasks to which participants referred.

Oftentimes, participants identified specific devices to rectify the situation. People in the Northeast stroke group talked about gadgets to hold breads in place, such as bagel slicers or cutting boards. A group member in the Midwest suggested it would be advantageous if digital clocks could have a reverse function so that users could set the time without having to make full revolutions around the clock face. Keyguards were mentioned for computers, shoes with velcro were cited, and speaker phones were considered as a possible solution for note taking and conversing.

Although many solutions exist, several people expressed interest in seeing more devices developed or adapted that take into account the needs of people who cannot use both of their upper limbs. Some kind of stabilizer was recommended to keep devices anchored in position.

OBSERVATIONS REGARDING PRODUCT FEATURES

The ten product features identified by EIF/REC focus group participants can provide designers and manufacturers with much information about the needs of consumers with disabilities. The desires of the focus group members are thoughtfully articulated and provide industry with many challenges. However, it is important to note that sometimes these features conflict with each other. For instance, manufacturers may find it economically unfeasible to develop products which include many of the cited features in tandem. Durable, lightweight, easy to assemble and disassemble devices with lengthened service contracts may be available at a price that most consumers are unwilling or unable to pay. Device manufacturers will have to identify trade-offs they must make in order to produce and market products that meet enough of these perceived needs to satisfy users.

HOW CONSUMERS WITH DISABILITIES LEARN ABOUT PRODUCTS

Information about consumer products is available to the general public including persons with disabilities, through television, radio, and magazine advertisements. When asked

how they learn about adaptive equipment, focus group participants cited many sources. They receive product information from professionals in the medical and rehabilitation fields, such as doctors, occupational therapists, and physical therapists in hospitals, clinics, and adult day health programs. They find out about devices from family members and friends, through informal conversations. In support group meetings, they hear about products from other people with similar disabling conditions. Voluntary organizations like local chapters of the National Multiple Sclerosis Society, the National Head Injury Association and the United Cerebral Palsy Association provide additional referrals. Catalogues, libraries, and disabled student services programs in universities they attend are also avenues they explore. Occasionally, articles in the press address specialized technologies for persons with disabilities.

Although many information sources exist, people often seemed to have problems learning about technologies. This finding is consistent with information obtained in the first year of the study.(7) When asked to identify "wish list" items they wanted, several consumers mentioned devices that are commercially available. For instance, one person in the Northeast CP group wished for a blow dryer on a stand so she could style her hair with one hand. However, she did not know such a product could be purchased. In a variation of this same theme, family members or friends created homemade versions of devices (such as playing card holders) because they could not find them in the marketplace, even though this equipment is obtainable. A person in the Southwest MS support group explained it this way, "People are unaware of half the things available to us electronically. How many people are aware of voice synthesizers, voice controlled computers, and the like?..." Clearly, product data is not being disseminated adequately to persons with disabilities.

DIFFICULTIES CONSUMERS HAVE IN CHOOSING DEVICES

Several participants discussed the problems inherent in getting out and shopping for consumer products of any kind. Many people need the assistance of another human being in order to go outside the home. Hunting for devices is often not a major priority. Since transportation and public facilities are frequently inconvenient or inaccessible to persons who experience functional limitations, such excursions may prove to be logistical nightmares for consumers with disabilities.

Besides problems engendered by the physical act of seeking devices, consumers may not know what they will want or require in a given product. Although a specific device is often prescribed by a rehabilitation professional, that is not always the case. For instance, a participant in the Midwest multiple sclerosis focus group commented on the experience of buying her first wheelchair. She was on her feet most of the time and was quite tired. Additionally, she did not know what features would be most beneficial to her once she became accustomed to using the product. Of course, needs often change over time. Her choice in that situation was based on a lack of adequate information on what her own

requirements eventually came to be. Her experience echoed that of consumers who participated in the first year of the EIF/REC study.(8)

Another issue influencing product choice is cost (discussed above in the section on Product Features) and the way devices are financed. Group members spoke about the vagaries of various funding programs, and what third-party payors will or will not cover. Two examples were cited in the Southwestern MS focus group. Often, private insurance will fund an electric scooter but will fail to cover the cost of a lift. Programs that provide funds to assist persons with disabilities to return to the workforce, such as state offices of vocational rehabilitation, will finance some products but will not pay for devices that may make it easier and less fatiguing to go to work. Consumers with disabilities face a "Catch-22" situation in trying to figure out what programs, if any, will assist them in financing products they want and need.

It is interesting to note that consumers often lack knowledge about existing programs and services that can help them procure devices. This is true even though EIF/REC focus group participants are affiliated with agencies in their communities that recruited them to take part in this research project. While many do gain valuable information from local resources, they were very eager to learn more about available products and financing initiatives. When social services providers introduced and sat in on the focus group sessions, participants would ask them to explain local programs and services as well as financing mechanisms for assistive devices. Attendees showed interest in learning more about such projects from which they could benefit.

TRADE-OFFS IN USING DEVICES

Consumers generally recognize that there are both advantages and disadvantages to using different kinds of products. For instance, a remote control device for a television can allow individuals to flip the dial without leaving the chair. Although this device is a convenience, people often comment that remote controls are turning them into "couch potatoes." Other examples include cumulative trauma disorders, health problems (e.g., carpal tunnel syndrome) which can be caused by repetitive motions on devices such as a computer. These conditions are becoming recognized as occupational hazards.

Just as other consumers do, people with disabilities weigh the benefits and drawbacks of devices they employ. Sometimes doctors will recommend that individuals obtain a device to make tasks easier to accomplish, to help persons conserve their energy, or to perform an activity safely. Consumers may feel that relying on equipment will cause them to lose functional abilities they still have. Use of a device they fear, may create premature dependence. A Midwest focus group member with multiple sclerosis summed up the dilemma this way, "You can push yourself too much and get worse, and then if you don't push yourself enough then you can get worse because you're not using everything." Another Midwesterner, a participant in the traumatic brain injury group, discussed her

ambivalence about using equipment. She mentioned that she no longer uses a wheelchair. She said, "I had to work for it. For those who are limited regardless, these devices make sense. But others should work for a chance to do things."

For some attendees, as in the case of a Northeast participant in the traumatic brain injury group, devices are perceived as a "step backwards." She explained, "I'm priding myself in being able to deal with my shortcomings and not to have to depend on [devices]...." A young woman in the Northeast cerebral palsy group remarked, "I don't have any special devices because at home, we [my family and I] don't think of myself as handicapped. I can do anything, I just need to hold on." Other people acknowledge that attitudes towards devices depend on the stage individuals have reached in their rehabilitation. Often, devices allow individuals to do activities that they would be unable to accomplish alone otherwise. For example, a participant in the Midwest MS focus group explained, "...the reacher allows me not to bend over so many times and take that chance of either falling or hurting my back...." Many people cited the convenience and value of the devices they use in daily life. The groups were very willing to explore the advantages and disadvantages of all kinds of appliances.

Other trade-off issues were considered. For instance, several focus groups wondered aloud whether the difficulties in learning to use certain devices were worth the effort. Some people found the computer elusive and frustrating; others saw it as a means to increase productivity. In the Northeast cerebral palsy focus group, a participant discussed abandoning an electronic wheelchair that was easy to operate for a manual wheelchair to increase her muscle strength. Conversely, a member of the Midwest traumatic brain injury group gave up her manual wheelchair for the independence she received from her three wheeled electric scooter after extensive battles with a third party payor for financial assistance. Additionally, one focus group weighed the implications of increasing the number of attachments on wheelchairs to transport packages and canes against the possibilities that these "add-ons" would make wheelchairs larger, more difficult to maneuver and more of a curiosity to on-lookers.

Many consumers reflect on the pros and cons of adding appliances to their possessions. Certainly, cost is a component in their calculations. Consumers with disabilities who participated in the second year of the EIF/REC research project are not unlike other consumers in that respect. Differences, when they occur, come in the way some of the trade-offs are identified and articulated. Each consumer makes such decisions based on criteria they formulate for themselves.

CONSUMER INTEREST IN TESTING DEVICES

Several focus group members expressed the opinion that products could be greatly improved through involving consumers with disabilities in product development and testing efforts. A number of participants praised the EIF/REC Consumer Needs

Assessment project, viewing the study as a means of including users in the process. These recommendations came from all regions of the country where focus group sessions were convened. Said one Midwestern multiple sclerosis focus group member, "I like the idea of letting disabled people try out equipment for a period of time and let them give their comments. Those of us that are here, that took the time and trouble to come here, people like us".

Consumers are ready and eager to test devices to ensure that they meet a variety of their needs. Attendees feel it is important for manufacturers to recognize the diversity within the disabled community and to take those requirements into account. Focus group members do not expect every need to be met in all situations. In fact, consumers within and across disability groups often disagreed among themselves. They defined their specific product needs uniquely and acknowledged their differences. Yet they want to participate in defining how products will be designed, tested, and brought to the marketplace so that more people can operate and benefit from equipment. Users hope that their personal involvement in this procedure will help them learn more about what products currently exist or may become available in the future that could assist them to function more effectively.

FOCUS GROUP OBSERVATIONS REGARDING SPECIFIC TYPES OF PRODUCTS

While each focus group discussed a multitude of products they use, want, or need, several kinds of devices generated special interest and were scrutinized. This section will discuss the following devices: controls (switches, dials, knobs, levers, and remote controls), computers, mobility devices (canes, wheelchairs, and vehicles -- automobiles and vans) and communication tools (telecommunication devices and augmentative communication boards).

CONTROLS

No consensus existed either within or among groups regarding the types of control mechanisms consumers can operate most easily. The advantages and disadvantages of each type of control were described. For instance, some individuals like knobs, but others cannot rotate them and prefer levers instead. Several participants favor push buttons. Yet some of their fellow attendees remarked that it can be difficult to place adequate pressure on push buttons (the example often cited is a microwave) to register the commands. There are those who like switches. Again, others disagree. Some group members commented that it is easier to pull switches rather than turn them. Although several participants like using dials, others have trouble setting them accurately on appliances such as washing machines or dishwashers.

It is clear from this diversity of opinion that consumers want a variety of controls. No single control satisfies everyone. Since their preferences differ, users can benefit from having choices available in the marketplace.

Focus group members identified certain product features that assist them in using control mechanisms. These characteristics, explained in detail above (see page 8), include size, location, texture, color, and brightness.

REMOTE CONTROLS

Although several people commented on the convenience of using a remote control device for the television, complaints about the product were also made. A participant in the Southwest traumatic brain injury focus group explained it accordingly, "...my TV control, I want to smash. I can't remember which one is which, it's too small, it's too confusing, and you know you hit the wrong button and all of a sudden the TV's gone all the way out." Several people recommended that remote control buttons and lettering be enlarged. Others found problems with flat panels that fail to guide them in selecting the correct push buttons. Raised keys seem easier to push for many participants.

In the Northeast multiple sclerosis group, participants mentioned the problem of aiming the remote control so that the channels would change on the television. Suggestions were also made regarding the control's placement so that it is located close by. One focus group member recommended having a velcro attachment or a chain on the device so that it can be placed around the neck. This would make it easier to find the control and ensure that it does not slip out of reach.

Of course, not everyone who participated in the focus groups uses or likes remote controls. Some cited the desire to remain independent of such a device, others considered the cost to be excessive.

COMPUTERS

As was the case in the first year of the study, computers commanded a lot of attention from second year focus group participants. With the exception of the Midwestern stroke focus group, where the subject did not come up, everywhere else it generated discussion. Groups view the potential of computer access very broadly -- as an aid in employment, as a tool in the rehabilitation process, and as a source for linking persons with disabilities to worlds outside their own homes. According to a member of the Northeast traumatic brain injury group,

> ...there are lots of other things that PCs [personal computers] can be used for -- retail, purchasing products, banking, and more important perhaps to us, if this information base is developed, actually being able to tap into that base from your living room, from your bedroom, whatever, wherever you have your PC....

Other users spoke of the computer's ability to help increase worker productivity as well as to enhance one's self-image. Group members who have computers commented on their many uses -- the organization of documents without paper clutter, the legibility of computer print-outs as opposed to handwritten materials, the ability to save information, and the recreation and stimulation of many computer games. Individuals also considered the role computers play in environmental control units.

Although group members recognize the benefits of computer technologies, they are able to suggest improvements to the product. First and foremost is the issue of cost. In the words of a computer consultant with MS who participated in a Northeast focus group:

> Computers offer the homebound a wonderful way to make a living. I could place people working in their homes. But the problem is making equipment available to them. An enormous number of occupations would be accessible if computers were more affordable.

Large screens were identified as a helpful tool for persons with visual problems. One member of the Northeast multiple sclerosis focus group, quoted above, had much to say about her research into the issue:

> The Apple screen is wonderful because it is almost virtually flat even though it's a 19 inch diagonal screen whereas a lot of them at lesser cost, you can't use. I tested E-screens, the SuperMac, Radius, they have just enough curvature that they're very fatiguing to deal with, if you happen to be struggling with optic neuritis.

Other obstacles to computer use were explored. In the Southwest multiple sclerosis focus group, people commented on the problem of seeing the computer screen and of experiencing stiffness and dizziness. Possible improvements recommended include an adjustable screen that can be tilted back and forth, and a way that the user can tell by the feel of the key which one is in operation. Also mentioned is the location of the Caps Lock key. Its placement bothered a group member who inadvertently pressed it regularly. In the Southwest traumatic brain injury focus group, the problem of repairing a computer was cited.

Not all focus group members are enthusiastic about computers. Several of them find this technology frustrating and confusing. They feel that it is too burdensome to remember all the steps to follow when using the machine and that it is difficult to interpret the manual of instructions. Some participants are simply uncomfortable with computers. As expressed

by a member of the Northeast stroke group, "People don't make mistakes no more, it's computers that make mistakes."

Several active users discussed attachments they employ to work on their computers. A Midwestern attendee of the cerebral palsy focus group has an extension on the computer disk drive where the disk is placed to assist in the process of loading and unloading it. During the time that the Southwest cerebral palsy focus group met, one member was in the early stages of learning to operate the computer with a head pointer. For several nonverbal participants or those with severe speech problems, talking computers are viewed as a future source for detailed, rapid communications.

MOBILITY DEVICES

No matter which mobility product was examined in the focus groups, individual members tended to equate the ability to get around with personal freedom. That is the reason why canes, wheelchairs and electric scooters, and motor vehicles were major topics of conversation. Whether individuals had abandoned the use of adaptive mobility equipment or depended on it extensively, focus group members had much to say about these devices.

CANES

Although many participants in the groups employ canes or did so during their rehabilitation, several people commented about the annoyance involved in not knowing where to put a cane when it is not in use (e.g., in a car, at a restaurant, in a public bathroom). Participants told stories of people who accidentally tripped over their canes. While several focus group members spoke about gadgets designed to hold canes in place, they mentioned that they are unable to master these devices because they do not have the strength to lock and unlock them. One person suggested placing velcro on a cane so it can be attached to a surface (like a wall), another recommended using rubber and thumbtacks in different settings.

Other issues surrounding canes include the importance of learning how to use them correctly. Aesthetics were also considered. One focus group member in the Southwest MS group suggested that canes come in colors other than black, brown, or metal. Perhaps because canes are perceived as medical equipment, attention to stylishness is an additional factor.

WHEELCHAIRS AND SCOOTERS

Besides cost, the most common complaint expressed in the focus groups about wheelchairs and scooters is their weight. Over and over, participants requested lighter equipment that they themselves could easily maneuver. Regarding manual wheelchairs, many focus group members asked for a device that could easily be transported (e.g., put into and taken out of a trunk or the back seat of a motor vehicle). Electric wheelchairs and scooters are even more problematic in this regard. There was excitement and interest in the use of space-age metals to reduce wheelchair weight, but also concern that the cost of such products might prove to be prohibitive.

Maintenance problems and long waits for repairs were articulated by focus group participants. Some of them seem to feel that electric wheelchairs tend to break down regularly. In cases where the control mechanisms fail, the chairs themselves are often too heavy to move.

Very basic concerns about wheelchairs cover the placement of purses, book bags, or canes in them. Groups also considered the issue of transporting packages. Some creative solutions to this problem were recommended. For example, one person attached two trash cans, one inside of the other, to the back of his wheelchair to carry items. People did comment that they would like carry-alls available at easier reach.

Several focus group members praise the electric scooters they operate. Said one Midwest stroke group participant, "...I use my three wheeled scooter quite a bit, especially when we go to the shopping centers and we do a whole lot of camping." The baskets on the scooters assist in transporting items. A Midwestern member of the traumatic brain injury group explained that without her scooter, "I would be bedbound or need to have someone lift me into a chair."

Although positive things were said about scooters, consumers did identify areas for improvement. One woman recommended limiting the hook-ups through which the machine battery could be energized. A Midwestern focus group member with MS mentioned that on hills, the scooter requires an extra push. A person in the Southwest MS focus group commented that his scooter does not exhibit a firm grip on a ramp during a rainy day. Finally, a consumer with MS in the Southwest discussed the location of operational buttons on her scooter. She finds the level at which her hands are positioned tiring.

In essence, wheelchairs and scooters are viewed as multipurpose devices. They provide transportation to those that operate them, yet they also assist consumers in moving items from one location to another. Groups considered the possibility of placing attachments to a wheelchair that would assist them in cleaning and vacuuming the house. Since many

people spend a lot of time using wheelchairs and scooters, it makes sense that they would recommend modifications that would provide them with additional benefits.

VEHICLES

The equipment that drivers with disabilities utilize varies greatly. Some require no adaptations. Others employ hand controls. Perhaps they cannot restrict their foot motion or they experience numbness that does not allow them to accurately judge the pressure they place on the gas pedal or the brake. Several people talked about steering knobs for drivers who have use of one hand and whether such devices are legal in their jurisdictions. Cruise control, which regulates the speed of the vehicle, and power steering, which facilitates the turning of the steering wheel by the driver, are readily available general market design features that assist several drivers with disabilities. Some participants explained they too want these features, but they cannot afford them.

Consumers spoke about safety issues related to driving. One member of the Midwest multiple sclerosis focus group told of the convenience of having a remote control garage door. Before it was installed, she fell repeatedly when attempting to close or lift the garage door. This problem was solved with the help of an electronic device.

Dealing with inclement weather is a concern for drivers who have disabilities. A Southwestern TBI focus group attendee suggested that carports be enlarged so that drivers would have protection when getting into and out of a vehicle in all weather conditions. A member of the Northeast MS focus group sought an alternative means to transport her wheelchair in her car without using a trunk lift (she feared falling in icy or rainy weather) or a car popper (a device bolted on the roof of the vehicle which she felt would deplete its resale value). Several people remarked on the importance of being able to contact someone in the event of an emergency on the road. The idea of a communications box near handicapped parking spaces was discussed in one focus group session. Participants mentioned wanting but not having car phones to deal with such contingencies.

Focus group participants identified other needs they manage while traveling by automobile or van. For instance, an attendee of the Southwest MS focus group carries a portable urinal in the car to avoid toileting problems on the road.

Consumers recommended improvements to vehicles. One participant suggested redesigning big, clumsy hand controls so they do not interfere with the operation of the car or van by non-disabled drivers. Perhaps vehicles could be programmed with memories of seat, light, or mirror adjustments so that they could adapt to several users. The idea of a standard raised seat that swivels out was promoted in one group, as was the possibility of push buttons or voice activated machines for gears.

For several people unable to drive, three wheeled bicycles are a means of transportation. This type of mobility device was prevalent in the Midwest groups convened and was also cited in the Southwest. Recognizing the importance of private transportation, one Midwest participant in the CP focus group wished for the development of a car operated by brain waves, so he could drive a vehicle.

COMMUNICATION DEVICES

The ability to express oneself, to share ideas and feelings is a human function often taken for granted. For many who have disabilities, the capacity to communicate is limited. Several of the focus group members across the four diagnostic groupings in this year of the study had communication problems. There were nonverbal participants, persons with aphasia, individuals unable to translate their thoughts into words, those with severe speech impediments and those restricted by their incapacity to leave home and socialize with others. Devices that assist such consumers in interacting with other people can broaden their world.

TELECOMMUNICATIONS TOOLS

Telecommunications devices can be important tools for users with disabilities. This phenomenon was highlighted in the Southwest MS focus group. There, a member who is paralyzed from the neck down used the Directel to participate in the session from his home. The Directel allows an individual to speak into a microphone and to hear responses through a loudspeaker. The device can be turned on and off with a plastic tube into which the user blows. It was operated in conjunction with a speaker phone placed in the focus group meeting room. The value of these technologies is evident from the attendee's comments. He opened his remarks by saying, "I really appreciate your allowing me to participate this way. It's the first time I've been able to get together with a group, it's great."

Several participants mentioned telephone company initiatives designed to provide greater access to telecommunications services for persons with disabilities. For instance, free directory assistance is available for those with disabilities who apply for it. Other services mentioned include speed dialing and predialing. Group members were interested in informing fellow participants who could benefit from these programs.

Focus group members like having easy, ready access to telecommunications devices. Several people in different focus groups remarked that they keep cordless phones by their side or rely on answering machines so they need not rush to receive a telephone call. One group member uses a long extender cord for her telephone. As observed elsewhere

in the monograph, telephones are often used as impromptu alert systems. Individuals employ them to seek outside assistance in the event of emergencies.

Participants had recommendations about ways to improve telecommunication tools. Although group members acknowledged that it is helpful to carry around cordless telephones, one group member sought better reception from his equipment. Others use speaker phones, but a member of the Midwest CP focus group mentioned that it is difficult for someone with speech problems to be understood on such a device, especially when it echoes. Conventional cord telephones, whether wall or table models, are problematic for many participants, particularly those unable to use two hands. One group member recommended having more telephones with a combination of memory, being lightweight, and with some kind of strap or neckrest to anchor it appropriately.

Attitudes towards phone dials or push buttons differ among and within groups. Some consumers find push button telephones easier to manipulate, others find the rotary dial easier, guiding the fingers to the correct numbers. Of course, thoughts regarding telephones with memories are diverse. There are those who perceive this feature as a convenience and others who feel it is a lazy way to proceed.

One of the most poignant comments regarding telephones came from the Southwestern cerebral palsy focus group. An attendee whose diction is difficult to discern wants a device that could make speech intelligible over the telephone she said, "So, that people could understand me." Clearly, the desire to communicate with others is very strong among consumers with disabilities, just as it is within the general population.

AUGMENTATIVE COMMUNICATION BOARDS

Since several members of the Southwest CP focus group use manual or electronic communication boards, the issue was addressed in detail during that session. As discussed earlier, one of the participants needed an interpreter since her communication device, a head corner board, was not working. Her spokesman explained, "She likes to go places, to movies. She likes really to get out and communicate with other people if possible. The problem is getting them to understand what she is saying, and that is a big thing." After that statement, the nonverbal people in the group made loud supportive noises to emphasize the veracity of the comment.

Communications devices were identified on individual attendees' wish lists. One nonverbal member of the Southwest cerebral palsy focus group wants an electronic communication board, mounted on a wheelchair, that is easier to use than the manual board currently in his possession. He prefers a device that has a voice synthesizer attached. A product that could explain one's thoughts and translate them into speech is sought by a Northeast stroke group participant who finds conversing difficult.

Communication with nonverbal participants in the focus groups occurred in several ways. In the Southwest traumatic brain injury group, one participant with limited verbal skills ensured that his views would be heard and understood. He wrote out a list of his concerns related to rehabilitation and presented it to the moderator of the group at the end of the session (see Attachment 2). In the Northeast traumatic brain injury group, some sign language was used and interpreted between two attendees. Attempts were made to solicit the opinions of people who could not articulate their thoughts. Sometimes family members spoke for them, and other times group members or the moderator attempted to interpret and sought to find out whether their explanation of the ideas were correct. Although these efforts were not always successful, there were times that ideas were clarified through this process. It required the patience from all those involved.

Problems obtaining information about communication devices were highlighted in the Northeast traumatic brain injury group. A participant mentioned the possibility that a nonverbal group member might benefit from using ditto sheets with common every day phrases and words he could point to. As one of his parents commented, "Because, you know, very little is available to us. We don't even know where to get..., nobody has even said to us about different types of communication boards and he's been getting speech therapy for eight years." The family was eager to gain additional information about existing products.

ACCESSIBILITY ISSUES

As was true in the first year of the Consumer Needs Assessment study, this year's focus group members expressed their frustration with logistical problems they face when functioning in the world outside of their homes. A member of the Northeast MS focus group explained the dilemma this way, quoting the famed musician Itzhak Perlman, "We want access with dignity." The obstacles individuals cite pertain to technology only peripherally. In fact, policies can be implemented and enforced that accommodate persons with disabilities in varied settings.

Attendees complained of dealing with steep ramps, poorly constructed and limited numbers of curb cuts, or inadequate railings that require them to seek assistance from other people. They resent having to enter buildings through rear or side entrances. Participants explained that they need to check restaurants, theatres, stores, and hotel rooms to see if they can use these facilities, since often buildings identified as "accessible" are unable to accommodate them. Such problems were universally identified.

Bathroom facilities can pose many problems for consumers with disabilities. Bathrooms may be unable to fit a wheelchair, have heavy doors that do not open and close easily, be located up or down a flight of stairs, or require patrons to pass crowded areas. In fact, one group identified a need for unisex bathrooms and dressing rooms in public places,

since people with disabilities may be accompanied by family members or attendants of the opposite sex who assist them in their personal care tasks.

Malls were a topic of conversation in the Northeast cerebral palsy focus group, the majority of whose members were teenagers. They discussed how aisles in stores are sometimes narrow, and fast food restaurants they frequent have tables that are all next to each other and bolted down. For those who use wheelchairs, it is problematic to eat out comfortably in such a setting. Revolving doors are another obstacle for wheelchair or cane users.

Shopping for food or clothes can be inconvenient. Consumers may need assistance to reach products on high shelves or manuever around merchandise stocked on the floor. Members of the Northeast traumatic brain injury focus group commented on the difficulty of relearning how to shop in a supermarket. The number of choices available and the varied location of products in different stores can seem overwhelming to these customers.

Other services are burdensome for focus group members. In the Midwest CP focus group, automatic bank teller machines came under scrutiny. Many people explained that they cannot reach the equipment from wheelchair height.

Some accommodations have been made in stores that either specifically help people with disabilities or result in benefitting them. One Midwest food chain provides customers with shopping cart attachments to wheelchairs. While an asset to shoppers, their size makes it difficult to go into the milk case or frozen food areas. In the Southwest MS focus group, a member discussed patronizing a pharmacy that has a drive up window. It allows him the luxury of buying medications from his van. Additionally, members of the Southwest MS focus group mentioned discounts they receive at theatres and other public facilities. Free parking is available to persons with disabilities in an area airport.

Participants remarked on the poor layout of many designated handicapped parking spaces and the lack of enforcement of parking rules. For instance, focus group members complained that there are not enough such parking spaces, they are not an adequate distance from other spaces, the number of ramps are limited, and drivers sometimes park over the ramps. Attendees across the country cited examples of non-disabled drivers who park illegally in handicapped accessible spaces without being disciplined for their actions.

Group members discussed their responsibility to act as their own advocates. Whether it be lobbying for the Americans with Disabilities Act (ADA), organizing advisory councils of disabled persons, or informing someone that they are illegally parked in a designated handicapped parking place, participants contended that individuals with disabilities "have to be assertive." As one Southwest MS group member explained, "You have to tell them. You have to make them aware."

KITCHEN SET-UP AND APPLIANCES

In many households, the kitchen is the center of much activity. This is as true for consumers with disabilities as it is for other people in the population. Focus group members shared many ideas about the way kitchens are organized and appliances constructed.

Participants mentioned that, because of height, cabinets are difficult for many of them to reach. Suggested improvements include lowering cabinets, installing lazy susans, and having doors that are easy to open and close. One person recommended sliding doors for her pantry area. Since many consumers with disabilities work in the kitchen from a seated position, the concept of lowering shelves in the refrigerator was also forwarded. In fact, one participant felt that refrigerator doors do not open out far enough. So, he recommended developing an electronic device that could move shelves closer to the user. A discussant in one group commented that frost free refrigerators are easier to use than defrosting with a pan of water.

Consumers mentioned the problem, when cooking, of carrying water from the sink to the stove. One person recommended installing the stove near the sink. Another participant told of using a hose extension to bring water to the kitchen basin.

Several focus group members want oven or dishwasher doors that swing out instead of the using conventional appliance doors (those that open down). Standard doors can be obstacles to wheelchair users. Often, they have to take off the wheelchair foot pieces to get close enough to the device, or they have to go to the side of the appliance to place or remove food or dishes. Such issues were also raised in focus group sessions convened in the first year of the Consumer Needs Assessment Project.

For those who are seated when they cook, traditional stoves are unpopular for safety reasons: back burners cannot be reached without the danger of injuring oneself if the front burners are already in use and pulling out oven racks can be dangerous for the user with impaired sensation. Dials on stoves are often too high and far back to reach. Microwave ovens have become popular alternatives.

Several focus group members use adaptive food utensils to eat. Dycem, a rubber substance that anchors plates, is employed. Drinking straws can be useful. One woman in the Northeast stroke group put it simply. She said, "I would love a knife that cuts." She explained that she lives alone and can't always cut her food. In her words, it disturbs her that she is unable to eat her meal in a "ladylike fashion." The irony is, there are probably devices out in the marketplace that could assist her to do that very thing.

Clothes washers and dryers were also a topic of discussion in several groups. For many, it is difficult to accurately set the dials or place clothing in and take it out of the washer and

dryer. One focus group member prefers having a washer that loads from the side instead of from the top. A person recommended that a combination washing/drying machine be developed, perhaps placing some kind of conveyor belt between the two devices so that the task could be accomplished. Another wish list item is for an appliance that could wash, dry, and fold clothes. Additionally, the issue of instructions for using these appliances was considered. A member of the Midwest TBI focus group remarked that it was difficult to follow instructions for using these devices soon after his accident.

GROOMING AND DRESSING

While not a technology issue per se, participants had many reflections about the clothing they wear, and how they manage their grooming needs. Sweat suits are considered "a blessing" since they are easy to get into and out of and everybody wears them. Many group members have problems fastening buttons. A member of the Midwest MS focus group told how her mother replaced buttons with velcro on all of her outfits. Sneakers with velcro closures are popular with many participants, as are turtlenecks that require no fastening. Snaps and zippers are easy to use for some of the attendees.

Some focus group members employ specialized products, such as button hooks or sock aids to assist them in dressing. Others find these devices unwieldy to operate. One focus group member mentioned he wears slip-on ties. Another person, unable to use one of his hands because of a stroke, wants a pair of trousers with both pockets on one side, so he can have easy access to them. Placing clothing at easy reach was another issue raised. If clothes are hung at wheelchair height or racks could be lowered mechanically, it would be simpler for many group participants.

Grooming concerns also came up. In the Southwest cerebral palsy focus group, several issues were covered. One person seeks a device where she could comb her own hair, another spoke of difficulties in opening a make-up compact, and a gentleman wants a gadget that will hold his razor while he shaves. A participant also requested means by which she could manage her toileting needs without the assistance of a personal care attendant.

Participants employ many methods to take care of grooming needs. Some people go to beauty parlors to have their hair done. One participant in the Midwest MS focus group has make-up in different parts of the house so that if she is going out, she need not make an extra trip upstairs to retrieve a compact. Other people employ electronic toothbrushes, Water Piks, or Interplaks for brushing teeth. Electric razors are favored by many participants.

Many bathrooms are outfitted with railings, raised toilet seats, moveable shower nozzles, tub benches, and rubber mats to help prevent falls. Safety and convenience are primary concerns here.

WISH LIST ITEMS

The richness and diversity of individual needs are reflected in the variety of wish list items participants identified. The majority of the desired products already exist in the marketplace, but the participants did not own them. Either as consumers, they were unaware of their commercial availability or they could not afford them. Other wish list items have not been created at the present time. Some of the products mentioned were high technology devices such as a machine that can take the spoken word and turn it into written text or a product that can allow individuals to do their computer work by voice with a modem that adapts to different speech inflections. Not all the suggestions were sophisticated technologies. For instance, one participant wanted a mop with a lever so that wringing it out is made less difficult and another person sought a sidepack to carry books on a wheelchair. Wish list items appear that have nothing to do with technology per se. For example, a member of the Southwest focus group unable to attend the session in person commented, "Boy, I would love to get out." Others spoke of "being like other people" and "going swimming, horseback riding, or running again."

The following inventory identifies wish list items not mentioned previously in other sections of this monograph. The lists are divided by disability group, not because differences are apparent across diagnostic categories, but rather to highlight both the assortment of needs described within groups and the duplication of needs among people who participated in the focus groups. Some descriptions will be included where commentary will clarify what is sought. Although the lists are not exhaustive, they reveal the range of perceived needs consumers with disabilities have.

CP Focus Group Wish List Items

<u>Electronic and Electrical Devices</u>

- Telephones with screens so users can look at the other person when speaking.
- Voice activated telephone, so there is no need to dial.
- Automatic door openers on all houses.
- Aid to lower cabinets so upper shelves could be reached.
- Remote control to play VCR tapes.
- One remote for all kinds of switches.

- Escalators with steps wide enough to accommodate wheelchairs.
- Attachments to wheelchairs or scooters to replace brooms or vacuums.

Mechanical Devices

- A lift to get in and out of bed/the tub.
- Can opener large enough to fit a huge can.
- Device to carry things around the house, like a stroller.

Other Wishes

- Need more curb cuts.
- Need more devices for left-handed persons.

MS Focus Groups Wish List Items

Electronic and Electrical Devices

- Reasonably priced large telephones with memory.
- Portable air conditioner for going outside in the summertime.
- Way to unlock door without a traditional key.
- Bathroom doors that work like electronic garage doors, they move up instead of pull out.
- Electronic device that follows user around to transport things.
- Attachments to scooters or wheelchairs that could clean and vacuum the home.
- Inexpensive emergency alert systems for people with disabilities.
- Device for turning the pages of a book by voice command as an add-on to the Kurzweil Personal Reader.
- Device like a jukebox that could pick up a VCR tape, place it in the machine, play it, and release it when done. It could possibly have attachments for other items like a compact disk (CD) player, dish washer, and washing machine.

Mechanical Devices

- Compact, moveable work station that has a backrest and feet on it so that one could sit, transport things, and step on it to reach materials.
- Small light Airdyne bicycle.
- Child seat or grab bars to transport a child in a scooter.

Other Wishes

- Something to get an individual's "arms and legs to work, but that is not in the realm of reality."
- More discounts, similar to those given to senior citizens.

Stroke Focus Group Wish List Items

Electronic and Electrical Devices

- Device to help individual seek and find words.

Mechanical Devices

- A hand grip on a bed mattress so user can move about the bed more easily.
- One handed letter opener.
- Lighter wheelchairs.
- Grooming device to cut toenails.
- Something to anchor down a piece of meat so you can cut it.
- Bicycle that person with paralysis on one side could use.
- Folding chair that can be pushed with one's feet.
- Noiseless velcro.

Other Wishes

- New body parts.

- Being able to fish on a dock.
- Human companionship.

TBI Focus Group Wish List Items

Electronic and Electrical Devices

- Tinnitus suppressor to eliminate head noises.
- Electric window openers.
- Door openers.
- Riser for wheelchair or other chairs.
- Buttons to move curtains, clothes rods.
- Moving doors.
- Garbage disposal.
- Light-weight, high suction vacuum cleaner.
- Vacuum system in the walls -- hose with plug.
- More voice activated devices.
- Computer.
- Electrical safety knife.
- Small cassette tape recorder.
- Communication board for non-verbal person.
- Beeper reminder to take medications or accomplish other tasks.

Mechanical Devices

- More durable velcro.
- Stabilizer for paper when writing.

- For those who have lost the sense of smell and/or taste, a device the user could stick into food to tell whether or not it has spoiled (perhaps it could change color to indicate whether spoilage has occurred).

Other Wishes

- Chauffeur.
- Well-paying employment.
- More information on what is available to assist persons with disabilities.
- Increased compassion by medical and rehabilitation professionals.

CREATIVE SOLUTIONS

Besides identifying items they want, the moderator asked all focus group members to share examples of creative ways they cope with needs they have. At times, individuals turn to devices for assistance. Some products are one-of-a-kind homemade inventions, like a cutting board with aluminum nails used by a member of the Midwest TBI focus group or the hand rails placed in the home of a Southwest TBI participant. Such devices are produced and sold but individuals either did not know that or felt they could devise an inexpensive alternative. Other products are more specialized and not necessarily obtainable on the open market. One example is a baby seat that rolls on the floor which an individual who attended the Midwest CP focus group session uses to feed, diaper, and romp with his children. Another item is a wooden track that allows a user to guide disks into a computer.

Some solutions are adaptations of commercially available products. They rarely involve high technology. For instance, a member of the Midwest stroke focus group had a stand built under his Lazy Boy rocker to help him place his feet on the floor, and push himself up more easily. An attendee of the Midwest MS group transports hot food by using her wheeled dining room chairs as trays. A Southwestern participant with MS employs pliers to turn dials on the stove. A member of the Midwest cerebral palsy group discussed how he utilizes clothes pins instead of twist ties on bread packaging. Using one's cane as a reacher is a common practice as is placing a foam hair roller over a pen or a pencil to make it thicker and easier to grasp. Frequently, problems are solved when consumers with disabilities employ existing devices in ways that differ from the original purpose for which they are created.

Not all solutions are product-oriented, sometimes they involve changes in the ways tasks are accomplished. For instance, a member of the Northeast traumatic brain injury group discussed methods he uses to remember to do chores. When grocery shopping, he

brings two lists. He attaches one to the grocery cart with little magnets, the kind one often places on the refrigerator. He keeps the other list in his pocket as a back-up in case the first one is misplaced. He also leaves himself reminder notes in places or on things he routinely goes to, i.e., the coffee jar, the TV Guide. This system works well for him.

Other coping mechanisms used by focus group members include receiving help from family and friends. When asked by the moderator what device they depend on most, many people answered, "my spouse" or "my parents." Explained a member of the Northeast stroke group:

> Now, I've got a stroke. My whole life changed. I find it very difficult to adjust to it, you know. Thank God, I have a wife, she takes care of me, with everything, bathing, cleaning, medicines.... She's been with me for fifty years, so that's the only thing I rely on.

Focus group members also employ people to assist them. Some participants mentioned that they go to the beauty parlor to have their hair done as opposed to doing it themselves. They hire helpers to cook, clean, or help them with personal care tasks, depending on their financial circumstances and capabilities.

For those who live alone and do not have immediate family nearby, several concerns were articulated. Commenting on her particular situation, a member of the Northeast stroke focus group said:

> Sometimes you wonder if you would be better off if you never had a cent. I mean, because when you get to this stage, you keep worrying, "what's going to happen to me?..." Am I going to have to go into a nursing home in the end or can I afford to have somebody come in? Because now I don't have anybody come in. You can only afford so much.

GENERAL OBSERVATIONS AND CONCLUSIONS

Just as in the first year of the Consumer Needs Assessment Project, this year's focus group members were forthcoming in sharing their ideas and opinions. The wealth of information individuals provided is evidenced throughout this monograph. While the document details the major findings from the meetings, other issues of interest surfaced.

Many of the issues attendees raised can be viewed as a consequence of the stage of life the individuals are experiencing. Newly disabled persons who participated in the focus groups are less likely to view adaptive technology as an important element in their day to day existence. They seemed most interested in regaining functional ability through the rehabilitation process. Products, while of interest, are not a primary concern. Those who have lived with disabilities over a period of time generally seem more comfortable and

attuned to device use. As was the case in the first year of the study, no one appears to view technology as a panacea, an answer to all their needs. Rather, it is a tool -- one that many of the focus group members prefer using over other alternatives. Of course, there were attendees who are not captivated by the idea of technology.

Consumers tend to explain their needs within the context of their activities. For instance, teen-agers who participated in the Northeast cerebral palsy group discussed how products affected their ability to do their school work and to conduct their social lives. Sometimes, employed participants raised product concerns in terms of what occurs in their workplace. Parents of young children spoke about issues related to child care and rearing such as baby cribs or car seats. People at the latter stages of life emphasized their worries about loss of companionship, independence, and the specter of nursing home care.

Several groups noted that the aging of the population could have ramifications for the way in which products are designed. As people live longer, they reasoned, they are more likely to develop chronic limitations that will cause them to need and seek equipment that serves them and accommodates their needs. Focus group members felt that this expanding market may benefit all people with disabilities. Manufacturers, they argued, may be more interested in creating products for a substantial portion of this nation's population.

In some groups, sensitive topics were mentioned. At times, the issues were met with nervous laughter by attendees as when a consumer spoke of the desire to be able to take care of her toileting needs without the assistance of someone else. Other times, chatter erupted once a subject was introduced. When a participant in the Southwest MS focus group talked about products to help cope with sexual dysfunction, other group members chimed in. There were situations where points were forwarded only when the group disbursed and individual members spoke privately with the moderator. In the Northeast stroke group, a participant remarked that she uses incontinence products and finds them very helpful. Yet, she felt ill at ease in sharing this information during the course of the focus group session. These incidents highlight many areas ripe for research that can help to further identify and clarify the diverse needs of persons with disabilities.

It was clear that groups enjoyed sharing information with each other and seeing themselves as mutual resources. Individuals were eager to learn about products and to impart their knowledge in the group process.

Attendees were given financial compensation ($25) for their participation in focus group sessions. That provided some people with an additional incentive to participate in the meetings. Several group members were delighted that researchers were interested in their ideas and willing to compensate them for their involvement in the study.

Group members expressed the hope that what they had to say would be taken into account by device manufacturers, policy makers, rehabilitation professionals, and others

who review the study findings. One participant framed the issue this way, "I just have a question. After all these things we've told you, is there someone you can talk to who can actually make a difference about what we all talked about?" Focus group members want their words turned into action.

The second year of the Consumer Needs Project revealed several striking realities. The diversity of participants was evident both within and among groups. Whether a group consisted of persons with cerebral palsy, multiple sclerosis, head injuries, or stroke, focus group members commented repeatedly on how much individuals with disabilities differ. "No two are alike" was the message echoed during these sessions. There is no easy way to characterize group members and how they cope with their needs.

Yet, given this diversity, it is important to note that common issues and themes emerged from the focus group sessions. Participants were able to identify specific product features that both positively and adversely influence their ability to operate equipment. This monograph catalogues these design considerations. They include cost, durability/strength, maneuverability, ease of assembly and disassembly, repair issues, height, location, size, texture, color, and brightness of controls, safety features, simple instructions, aesthetics, and the ability to keep devices anchored while in use. Examples given by users themselves have been cited to explain the importance of these features.

This document examines specific products and policy issues that consumers with disabilities have identified as having an impact on their daily lives. In the subsequent years of the research project, the EIF/REC seeks to add to the current databank of information on the needs of consumers with disabilities. The project shows that there is much to learn from consumers themselves. The key is to ensure that this information is disseminated and that timely action is taken to incorporate the needs of this very diverse population into actual products and services.

ENDNOTES

1. See Phillips, L., "Consumer Needs Assessment: A Qualitative Study of the Needs of People With Disabilities, Results of the First Year of a Five Year Study," Washington, D.C.: Electronic Industries Foundation, 1989.

2. See Acknowledgments, located at the beginning of this paper, for information regarding the geographic diversity of the focus groups convened in Year 2 of the Consumer Needs Assessment Project.

3. See Phillips, pg. 3.

4. See Harkins, J.E. and Jensema, C., "Focus Group Discussions with Deaf and Severely Hard of Hearing People on Needs for Sensory Devices," Washington, D.C.: Gallaudet Research Institute, 1987.

5. See Phillips, pg. 5.

6. See Phillips, pg. 6.

7. See Phillips, pg. 6.

8. See Phillips, pg. 12.

ATTACHMENT 1: MODERATOR'S GUIDE

Introduction:

The goal of this discussion is to find out, from your perspective, about types of technology that can help you in your daily life. I ask you to share your opinions on devices that fall into two broad categories:

- devices specially designed to assist persons with disabilities -- wheelchairs, augmentative communications devices;
- general consumer products -- telephones, tv's, ovens, refrigerators, computers.

The aim is to consider what works for you, what doesn't, and why. This research seeks to discover whether and/or how devices can be improved to better meet your needs.

Questions:

Briefly describe what limitations you have that are caused by MS, CP, stroke, head injury?

What devices, either adaptive equipment or general consumer products, do you use to help you compensate for physical limitations? For what purposes do you use these devices?

What appliances do you have in your home? (Include remote controls)

Are you able to use all the appliances in your bathroom, bedroom, living room, kitchen, and in other rooms in the house? If not, why not? How do you manage other activities such as laundry, housekeeping, eating, other?

Back-up question regarding a typical day (if this information is not gathered through earlier inquiries):

What devices do you use in a typical day? When you:

- get up in the morning,
- use the toilet,
- bathe,
- dress,

- put on makeup or shave, brush your teeth,
- communicate with people who are not within of your home,
- prepare meals,
- clean the house,
- do laundry,
- leave the house,
- have free time,
- are employed?

If you had to choose one device that you depend on the most, what would it be? How would you manage without it?

What features do you like about this device? Why?

What features don't you like about this device? Why?

If you had to choose one device that you most enjoy using, what would it be? Why?

If you had to choose one device you do not like to use, what would it be? Why?

Can you discuss in general, features that you like or dislike in devices (e.g., size, weight, shape, appearance, cost, knobs, switches, dials)?

Are there devices that you have used and abandoned? Or devices someone gave you that remain in your closet? Why do you not use them?

What in your estimation, makes a [name a device identified within the group] easy to use? Difficult to use? Please be specific if you can.

Have you thought about ways that both specially adaptive devices and general consumer products you use could be improved? Cite examples.

Have you developed creative solutions to help you function more effectively? Have you, in any way, adapted devices to make it easier to accomplish your daily activities?

Questions to pose if time and flow of conversation so permits:

What features in _____ would you be willing to sacrifice to reduce its cost?

How do you learn about the products you use?

Where do you obtain these products?

How do you pay for such products? Are there products you have wanted that you have not been able to find external sources to pay for? What are they?

How accessible is your home (doors, stairs, heights & widths, thermostats, knobs, faucets, latches, plugs, access to light switches, ability to open/close windows)?

What changes could be made within your home to increase your ability to function there? What obstacles exist to making those changes?

What about activities outside of the home? Let's discuss issues related to public and private transportation. How do you get around?

What kinds of activities do you participate in outside of the home (sporting events, concerts, meals out, shopping)? What issues do you need to take into account in participating in such outings?

What piece of equipment do you wish you could have? Is there something you like to see invented that doesn't currently exist? What is it?

Is there any topic related to technology that we still need to cover?

Are there any other issues we need to cover?

Thanks and conclusions.

Goals for rehab ~~centers~~ centers:

- A. Have drivers evaluaction machines, big enough, for people with long legs to be able to use their feet, not having to use their weak side.
- B. Have a study ~~class~~ course for those going to take their drivers evaluation.
- C. Have an on the job training ~~corse~~ course.
- D. Transportation from any where in the ~~district~~ district. from their house
- E. A place to live with supervion.

let peopl know of it.

[redacted]